Swiss Childhood Cancer Registry
Schweizer Kinderkrebsregister
Registre Suisse du Cancer de l'Enfant
Registro Svizzero dei Tumouri Pediatrici

UNIVERSITÄT BERN

Jahresbericht
Rapport annuel
Relazione annuale

Annual Report 2007/2008

Swiss Childhood Cancer Registry

Annual Report 2007/2008

Claudia Kuehni
Gisela Michel
Myriam Pyrlik
Marie-Pierre Strippoli
Martin Adam
Cornelia Rebholz
Corina Rüegg
Gerrit Viehmann
Marianne Reck
Felix Niggli
Heinz Hengartner
Nicolas von der Weid

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Publisher: Swiss Childhood Cancer Registry
(PD Dr. med. Claudia Kuehni)

Address:
Institute of Social and Preventive Medicine
University of Bern
Finkenhubelweg 11
CH-3012 Bern
Switzerland

Tel.: +41 (0)31 631 38 99
Fax: +41 (0)31 631 36 48
E-mail: kinderkrebsregister@ispm.unibe.ch

Homepage: www.kinderkrebsregister.ch
Logo: Elsbeth Kuehni

Bern, Swiss Childhood Cancer Registry

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Table of content

1 Introduction

The Swiss Childhood Cancer Registry (SCCR) is a national population-based cancer registry for children in Switzerland. Since 1976, it registers new cancer diagnoses, clinical information and details on treatment and long term follow-up (survival, second tumours and late effects). Thereby it contributes to understanding causes of cancer in children, improving treatment and avoiding late effects.

The SCCR is located at the Institute of Social and Preventive Medicine (ISPM) at the University of Bern and closely cooperates with the Swiss Paediatric Oncology Group (SPOG). All Swiss paediatric haematology-oncology clinics report each new patient to the registry and send annual updates thereafter. To improve completeness, since 2007, the SCCR also collects data from other sources (other hospitals, pathology reports, exchange of data with general cancer registries in cantons where these exist). By Dec 31, 2007 data from 5548 patients have been registered. The Swiss Childhood Cancer Registry is a member of the International Association of Cancer Registries (IACR) and the European Network of Cancer Registries (ENCR) and has cancer registry permission from the Swiss Federal Commission of Experts for Professional Secrecy in Medical Research (Eidg. Expertenkommission für das Berufsgeheimnis in der medizinischen Forschung), allowing collection of non-anonymised data.

The SCCR collaborates with the National Institute for Cancer Epidemiology and Registration (NICER, the former Association of Swiss Cancer Registries (VSKR)), the German Childhood Cancer Registry in Mainz (GCCR), the National Registry of Childhood Tumours in the UK in Oxford (NRCT) and other national childhood cancer registries.

This third annual report covers routine analyses of all children diagnosed between Jan 1, 1976 and Dec 31, 2007. Data on children diagnosed late in 2008 are not yet complete and will therefore be covered in the next annual report. In contrast, activities and projects of the SCCR are reported for the whole period Jan 2007-Jun 2009. In particular, the report contains:

- an update on the organisation and staff of the SCCR at the Institute of Social and Preventive Medicine (University of Bern) and the participating paediatric haematology-oncology clinics of the SPOG (**chapter 2**)
- a summary of the data collected in the registry until Dec 2007 (routine analyses; **chapter 3**)
- current research projects of the SCCR (**chapter 4**)
- review of activities Jan 2007-Jun 2009 (structural projects, database, funding, data protection; **chapter 5**)
- publications (**chapter 6**).

We would also like to point out our website www.childhoodcancerregistry.ch for further information. Earlier annual reports, which can be downloaded there, contain a detailed description of the history of the SCCR and of past activities.

Finally, we would like to thank all the parents and their children, all adolescent and adult childhood cancer survivors, and all treating physicians and data managers of the Swiss Paediatric Oncology Group for their excellent and lasting cooperation. We also want to give thanks to all our supporters for their generous contributions. Particular thanks go to the “Kinderkrebshilfe Schweiz”, “Novartis”, “Astrazeneca”, “Interpharma”, “AXA Winterthur” and “Glaxo SmithKline” who support the daily running and continuous improvement of the SCCR, and “Oncosuisse”, the Bernese Cancer League, the Swiss Federal Office of Health, Federal Statistical Office, Cancer League and the Swiss National Science Foundation for supporting our research projects. A detailed list of all supporters is included in chapter 2 and in Table 11.

2 Organisation of the Swiss Childhood Cancer Registry

2.1 Staff

The Swiss Childhood Cancer Registry (SCCR) is run jointly by the Swiss Paediatric Oncology Group (SPOG) and the Institute of Social and Preventive Medicine (ISPM) at the University of Bern.

Institute of Social and Preventive Medicine (ISPM), University of Bern

Finkenhubelweg 11, 3012 Bern
Tel.: +41 (0)31 631 38 99 / +41 (0)31 631 35 15
Fax: +41 (0)31 631 36 48
E-Mail: kinderkrebsregister@ispm.unibe.ch

Scientists		
PD Dr. med. Claudia Kuehni FMH (Paediatrics), MSc (Epidemiology)	Head of SCCR overall responsibility	kuehni@ispm.unibe.ch
Gisela Michel, PhD	Research project: Follow-up care after childhood and young adult cancer	michel@ispm.unibe.ch
Martin Adam, MSc (Environmental sciences)	Research projects: Completeness of SCCR / Socio-economic status (SES)	madam@ispm.unibe.ch
Cornelia Rebholz, MSc (Environmental sciences) Corina Rüegg, MSc (Exercise & health sciences)	Research project: Swiss Childhood Cancer Survivors Study (SCCSS)	crebholz@ispm.unibe.ch crueegg@ispm.unibe.ch
Marie-Pierre Strippoli, MSc (Medical Statistics)	Statistician, routine analyses and research projects	strippol@ispm.unibe.ch

Administration, medical documentation and computer science		
Marianne Reck	Responsible for donations	mreck@ispm.unibe.ch
Myriam Pyrlik	Medical documentalist, SCCR Data Manager	mpyrlik@ispm.unibe.ch
Dr. med. Elisabeth Kiraly	Diagnostic Coding	kiraly@ispm.unibe.ch
Gerrit Viehmann	Medical documentalist, Study Data Manager	gviehmann@ispm.unibe.ch
Malcolm Sturdy	Computer Science	sturdy@ispm.unibe.ch
Philipp Läuppi	Web-Design and Web-Administration	plaeuppi@ispm.unibe.ch

Swiss Paediatric Oncology Group (SPOG)

SPOG Office
Effingerstrasse 40, 3008 Bern
Tel.: +41 (0)31 389 91 89
Fax: +41 (0)31 389 92 00

SPOG Executive		
PD Dr. med. Nicolas von der Weid	President	Nicolas.Von-Der-Weid@chuv.ch
Prof. Dr. med. Felix Niggli	Vice President	felix.niggli@kispi.uzh.ch
Dr. med. Heinz Hengartner	Secretary	heinz.hengartner@kispisg.ch

Central office in Bern		
Isabelle Lamontagne-Müller	Managing director, clinical trials, ethic committee submissions	isabelle.lamontagne@spog.ch
Barbara Kindler	Central administration	barbara.kindler@spog.ch

Participating clinics (Haemato-Oncology)		
	Head of Division	Local Data Manager
Aarau (Kinderklinik, Kantonsspital Aarau)	Dr. med. R. Angst	Dr. med. R. Angst
Basel (Universitätskinderspital beider Basel)	Prof. Dr. med. M. Paulussen	V. Stahel
Bern (Universitäts-Kinderklinik, Inselspital)	Prof. Dr. med. A. Hirt	F. Julmy N. Beusch
Genève (Hôpital des Enfants, HUG)	PD Dr. med. H. Ozsahin	M. Berner
Lausanne (Service de Pédiatrie, CHUV)	PD Dr. med. M. Beck-Popovic	Dr. med. R.-E. Garcia
Tessin **Locarno** (Reparto di Pediatria, Ospedale Regionale di Locarno) (until Dec 2007)	Dr. med. L. Nobile	Dr. med. L. Nobile
Bellinzona (Reparto di Pediatria, Ospedale S. Giovanni, Bellinzona)	Dr. med. P. Brazzola	Dr. med. P. Brazzola
Luzern (Kinderspital, Kantonspital Luzern)	Dr. med. U. Caflisch	Y. Bonetti
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Zurich (Universitäts-Kinderklinik, Zürich)	Prof. Dr. med. F. Niggli	H. Markiewicz

2.2 General information

The SCCR is an associate member of the International Association of Cancer Registries (IACR) and the European Network of Cancer Registries (ENCR).

Inclusion criteria and data collection

The SCCR registers all children and adolescents diagnosed with: i) Acute and chronic leukaemias, including myelodysplastic syndrome, ii) all solid malignancies, iii) all central nervous system tumours (CNS), including benign tumours, iv) Langerhans cell histiocytosis (LCH) and other histiocytosis (type I–III). Most children are reported from one of the nine Swiss clinics for paediatric oncology and haematology. A small proportion of patients (<10% of children aged <16 years) is treated in other hospitals, and information related to these cases is collected via other sources (cantonal cancer registries, other hospitals, pathologies, death certificates). We aim for complete registration of all children below the age of 16 years. Patients aged between 16 and 19 years are also registered, but registration is not complete because these adolescents are usually not treated in paediatric clinics. Children who are not residents of Switzerland but come here for treatment are also registered, but excluded from analyses of incidence and survival.

Follow-up data is extracted once or twice a year from the patients' hospital records for the first 5 to 10 years after diagnosis. Thereafter follow-up data are obtained from the patients' general practitioners or paediatricians. Very long-term follow-up occurs via direct contact to patients (see chapter 4: Swiss Childhood Cancer Survivor Study) and data linkage with mortality records and cantonal cancer registries. In each of the nine centres a local data manager completes the data forms. These are sent to the SCCR and entered into the database. Important documents (e.g. pathology reports) are scanned and saved under a pseudonym (ID number). Paper copies are destroyed.

Database

The new electronic database of the SCCR was developed by Malcolm Sturdy in 2006-2007. At present, the following information on cancer patients is being collected:

- Patient name, current address and phone number, and address at the time of diagnosis
- Name and address of the general practitioner or paediatrician and the paediatric oncology clinic treating the child
- Demographic information (date of birth, gender)
- Socio-economic information (parental profession, place of origin, country of residence)
- Tumour diagnosis, date of diagnosis, type of cancer, histology, stage, metastases
- Other diagnoses, relevant pre-existing disease conditions
- Clinical information and relevant laboratory values
- Treatment (treatment protocols, medication and dosages, radiotherapy, surgical interventions, others)
- Follow-up data concerning change of treatment, remission, relapses, survival/death and cause of death
- Late effects due to malignancy and therapy

Tumour coding

Until 2004, all tumours were coded according to the American Paediatric Oncology Group (POG). In addition, the exact diagnosis including details on location and staging was recorded. Since 2004 the SCCR codes new tumours according to the following international classifications (see Appendix):

1. The third edition of the International Classification of Childhood Cancer (ICCC-3)[1]
2. The third edition of the International Classification of Diseases for Oncology (ICD-O-3)[2]
3. The tenth edition of the International Statistical Classification of Diseases and Related Health Problems (ICD-10)[3]

Between 2004 and 2006, all tumours contained in the database were double-coded by two physicians according to the three new classification systems. To achieve this, all essential original reports (pathology, histology, radio-diagnostics) were collected from the hospital archives.

For presentation of data in the annual report we use the following classification for general diagnostic groups – a summary from the ICCC-3 classification: I. Leukaemias, II. Lymphomas, III. Central nervous system (CNS) neoplasms, IV. Neuroblastoma, V. Retinoblastoma, VI. Renal tumours, VII. Hepatic tumours, VIII. Malignant bone tumours, IX. Soft tissue sarcomas (STS), X. Germ cell tumours, XI. Other malignant epithelial neoplasms, XII. Other and unspecified malignant neoplasms. Langerhans cell histiocytoses (LCH), which are not contained in ICCC-3, are reported separately.

Completeness

Incidence of childhood cancers in the SCCR is similar to published incidence in cantonal cancer registries and in neighbouring countries (France, Germany and Italy).[4] This suggests that completeness of cases registered in the SCCR is comparable to neighbouring countries. Even CNS neoplasms, a problematic diagnostic group in many paediatric cancer registries, are relatively well covered, amounting to 24% of all cancers in 2001–2005. A first study in the 1980s, comparing completeness of the SCCR to cantonal general cancer registries, mortality statistics and hospital archives, suggested that in 1985-1988 the SCCR included 91% of all leukaemia cases recorded by the six existing cantonal registries and 80% of deaths due to childhood leukaemia in the mortality statistics in 1989.[5] In 2006-2008, a new validation study was performed by linking the SCCR with datasets from the cantonal cancer registries (Basel, Geneva, Grisons and Glarus, Valais, St.Gallen and Appenzell, Ticino, Zurich). This linkage suggested that in the period 1990 to 2004, 22% of children registered in the cantonal registries had not been registered in the SCCR (manuscript submitted for publication). Of these, 6% had been treated in a paediatric cancer centre of the Swiss Paediatric Oncology Group, but had not been reported to the SCCR, and 16% had been treated in other hospitals, including smaller children's clinics or adult wards. The proportion of patients not treated in a paediatric cancer centre decreased from 24% in 1990-1993 to 7% in 2002-2004. All missed patients who have been identified by this study have since been registered in the SCCR. Also, because of these findings, the SCCR now registers patients from various other sources besides paediatric cancer centres, via regular data exchange with cantonal cancer registries, and data collection from other hospitals, pathologies and mortality statistics. As a consequence the data protection situation changed and the SCCR received a general exemption instead of special exemption (see chapter 2.2.5).

[1] Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. International Classification of Childhood Cancer, Third Edition. Cancer 2005;103(7):1457-67.
[2] World Health Organization. International Statistical Classification of Diseases for Oncology - Third Edition (ICD-O-3). Geneva: World Health Organization; 2000.
[3] World Health Organization. International Statistical Classification of Diseases and Related Health Problems - Tenth Revision. Geneva: World Health Organization; 1993.
[4] Michel G, von der Weid N, Zwahlen M, Redmond S, Strippoli MPF, Kuehni CE. Incidence of childhood cancer in Switzerland: the Swiss Childhood Cancer Registry. Pediatr Blood Cancer 2008;50:46-51.
[5] Morin G, Ackermann Liebrich U, Imbach P. Childhood leukaemia in Switzerland: comparison of different sources of data. Soz Praeventivmed. 1993;38:196–201.

Data protection

Between 2004 and 2007, the SCCR has had a special exemption (“Sonderbewilligung”) from the Swiss Federal Commission of Experts for Professional Secrecy in Medical Research. During this period, written informed consent was collected from new patients and those still in follow-up.

Since June 2007, the Swiss Childhood Cancer Registry has general registry approval by the Swiss Federal Commission of Experts for Professional Secrecy in Medical Research. This approval permits the collection of data on cancer in children and adolescents throughout Switzerland without obtaining written consent. At the time of diagnosis all patients and their parents are informed by their doctor about the registry and they can ask their treating doctor not to forward their data (veto power). Records of these patients are completely anonymised. Huge efforts were made to inform all patients and their families, and all physicians in Switzerland about the registry, using various approaches (publications in official medical journals, oral presentations, letters to hospitals, physicians and parents organisations, and publications on the internet and in major newspapers). Information for patients is also available from hospital brochures, hospital notice boards, and parents and patients organisations. The patient data are kept strictly confidential in accordance with the requirements of the Data Protection Act and data with personal information (names, addresses) are kept separately from the medical information.

Further information on this permission can be obtained from the homepage of the Swiss Federal Commission of Experts for Professional Secrecy in Medical Research, at the Federal Office of Health. A copy of the document provided by the expert commission can be downloaded from our homepage (http://www.childhoodcancerregistry.ch/index.php?id=2451), together with publications in French and German explaining the data protection measures, and text proposals for insertion in patient information brochures of hospitals and for short patient information on notice boards in German, French and Italian.

Funding

The SCCR thanks the following supporters for their generous unrestricted financial support for daily running and continuous development of the registry. Supporters of scientific research projects are listed in Table 11 page 33.

Enduring supporters

Kinderkrebshilfe Schweiz

Swiss Paediatric Oncology Group (SPOG)

Current supporters 08/09

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Stiftung zur Förderung von sozialen Massnahmen in der Kranken- und Unfallversicherung

Bristol-Myers Squibb

Baxter

Mundipharma

Valiant Bank

Sanitas Versicherungen

3 Routine analyses covering cases diagnosed between 1976-2007

The section on routine analyses includes three chapters.

Chapter 3.1 describes the whole database, i.e. all children registered in the SCCR from 1976 to Dec 31, 2007 with a diagnostic code contained in ICCC-3 or a Langerhans cell histiocytosis (LCH), irrespective of age at diagnosis. This also includes adolescents older than 14 years, who are often treated in adult clinics and therefore only incompletely reported to the SCCR. Also included in this chapter are children resident in other countries who came to Switzerland for diagnostic work-up and treatment.

Chapter 3.2 includes the core group of children aged 0-14 years at diagnosis and resident in Switzerland at the time of diagnosis. This is the age group usually covered in international publications, and tables and figures can therefore be compared directly to data from other countries. Case registration in Switzerland is rather complete for this age range and incidence data can therefore be calculated.

Chapter 3.3 describes numbers of patients reported by different clinics of the SPOG for various periods irrespective of age and country of residence.

3.1 All cases registered in the SCCR (N=5548)

This chapter contains summary statistics for all children registered between Jan 1976 and Dec 2007. For children diagnosed in Nov or Dec 2008, some information (e.g. on treatment) is incomplete, and other information has not yet been validated (such as country of residence). For these reasons, data on children diagnosed in 2008 will be covered in the next annual report.

By Dec 31, 2007 a total of 5548 tumour cases with a diagnostic code contained in ICCC-3 or a Langerhans cell histiocytosis (LCH) had been registered in the SCCR. Of these, 4878 (88%) were Swiss residents at the time of diagnosis and 521 (9%) were foreign residents who came to Switzerland for treatment. For 149 children (3%) country of residence was unknown (**Table 1**). For retinoblastoma, 56% (156/277) of cases were foreign residents. This is mainly due to the Jules Gonin Eye Hospital at the University Hospital in Lausanne, which has treated 198 of the total 288 cases of retinoblastoma.

Systematic registration of all patients participating in clinical trials started in 1976 and the number of patients registered per year increased considerably after non-trial patients were included in 1981 (**Figure 1**). After 1994 annual registration increased only slightly. In the years 2006-2007, a total of 414 new patients were registered, 366 of whom were Swiss residents at the time of diagnosis (**Table 2**). For comparability with international datasets, only data from Swiss residents aged 0-14 years at diagnosis are included in further analyses.

Table 1 – Total number of registered cases in the SCCR, by country of residence

(including all age groups, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2007 (N=5548))

	All ages		0-14 years		>14 years	
Country of residence	**n**	**%**	**n**	**%**	**n**	**%**
1 Switzerland	4878	87.9	4539	87.7	339	91.6
2 Other countries	521	9.4	501	9.7	20	5.4
a Europe	371	6.7	359	6.9	12	3.2
Neighbouring countries*	228	4.1	217	4.2	11	3.0
Other European countries	143	2.6	142	2.7	1	0.3
b Middle East	10	0.2	10	0.2	0	0.0
c North Africa	78	1.4	72	1.4	6	1.6
d Other African countries	37	0.7	36	0.7	1	0.3
e Other countries	25	0.5	24	0.5	1	0.3
3 Country of residence missing	149	2.7	138	2.7	11	3.0
TOTAL	**5548**	**100.0**	**5178**	**100.0**	**370**	**100.0**

* Austria (N=7), France (N=59), Germany (N=50), Italy (N=101), Liechtenstein (N=11)

Figure 1 – Total number of cases registered in the SCCR

(including all age groups, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2007 (N=5548))

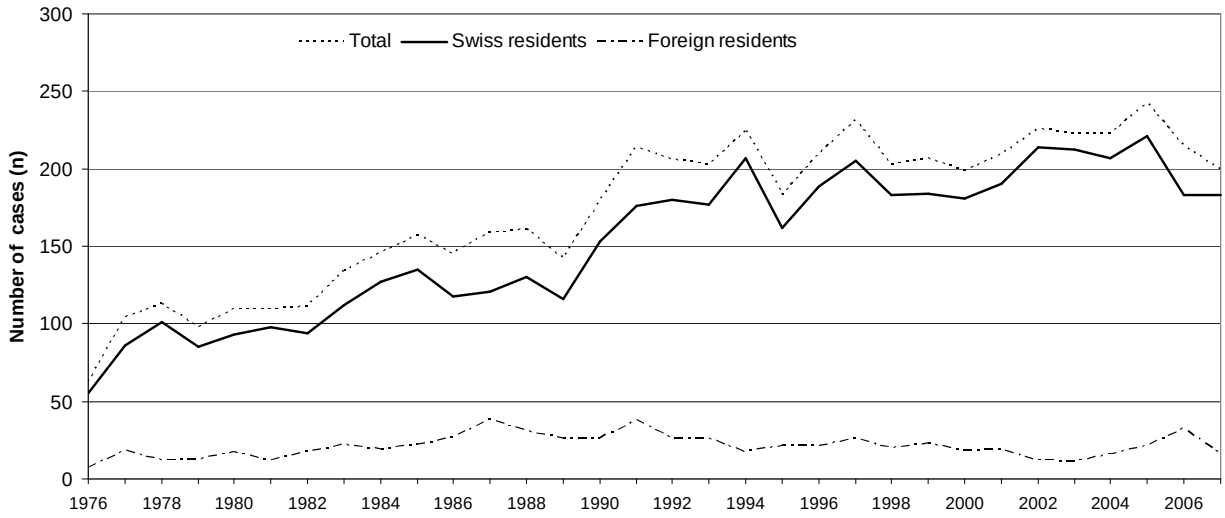


Table 2 – Number of cases registered in the SCCR (5-year intervals)

(including all age groups, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2007 (N=5548))

Year of diagnosis	All patients	Swiss residents, per period	Swiss residents, per year
until 1980	487	420	105
1981-1985	658	566	113
1986-1990	786	638	128
1991-1995	1030	902	180
1996-2000	1050	942	188
2001-2005	1123	1044	201
2006-2007*	414	366	183
TOTAL	**5548**	**4878**	**157**

*numbers for 2006-2007 are lower because this row includes only a two-year period, while the other rows include a five-year period of data collection.

3.2 All cases aged 0-14 years at diagnosis resident in Switzerland (N=4539)

This chapter includes only data on children aged 0-14 years and resident in Switzerland at diagnosis. This is the age group usually covered in international publications, and tables and figures can therefore be compared directly to data from other countries. Case registration in Switzerland is rather complete for this age range and incidence data can be calculated.

As of Dec 31, 2007 the SCCR contained data on 4539 children who were aged 0-14 years and who were resident in Switzerland at the time of diagnosis. Of these, 1105 (24%) had died and 847 (19%) were lost to follow-up. For 1494 cases (33%), the last follow-up information was reported after Jan 2005, for 501 (11%) and 592 (13%) the last follow-up information was collected in the period 2000–2004, and before the year 2000 respectively (**Table 3**). Currently (2008-2010) we are updating long-term follow-up information for all patients, using two approaches: active follow-up of survivors with postal questionnaires in the Swiss Childhood Cancer Survivor Study and systematic assessment of mortality via contacts with community registries and linkage with the Swiss mortality statistics (see chapter 4, research projects).

Nearly half of the cases (46%) had been diagnosed at the age of 0-4 years, 36% at the age of 1-4 years and 10% during infancy (less than 1 year of age) (**Table 4** and **Figure 2**). The number of cases per age group declines from infancy to age 9 years and increases again in older children (**Figure 3** and **Figure 4**).

One third of childhood cancers diagnosed in Swiss children between 1976 and 2007 were leukaemias (35%), followed by central nervous system neoplasms (18%) and lymphomas (14%, **Table 5** and **Figure 5**).

Table 3 – Number of patients in the SCCR databases

(Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2007 (N=4539))

Follow-up status	n	%
Died	1105	24.3
Last follow-up since Jan 2005	1494	32.9
Last follow-up 2000-2004	501	11.0
Last follow-up before 2000	592	13.0
Lost to follow-up	847	18.7
TOTAL	**4539**	**100.0**

Table 4 / Figure 2 – Age at first diagnosis

(Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2007 (N=4539))

Age in years	n	%
< 1 year	473	10.4
1 – 4 years	1635	36.0
5 – 9 years	1217	26.8
10 – 14 years	1214	26.8
TOTAL	**4539**	**100.0**

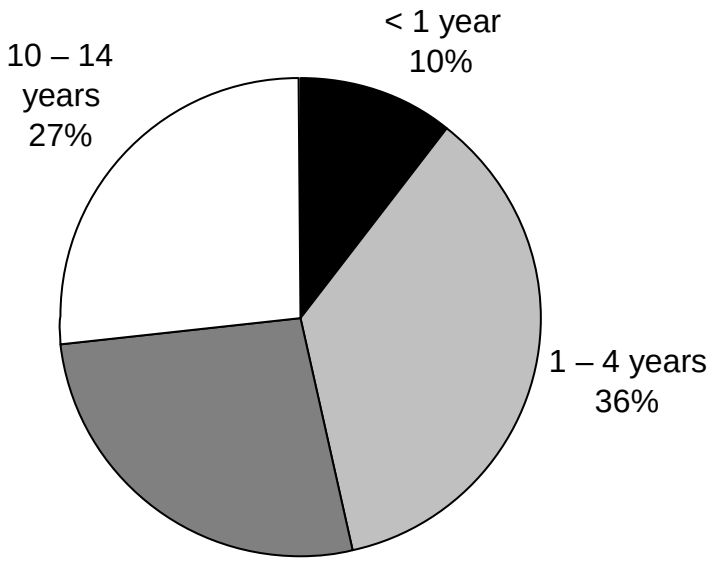


Figure 3 – Age at first diagnosis

(Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2007 (N=4539))

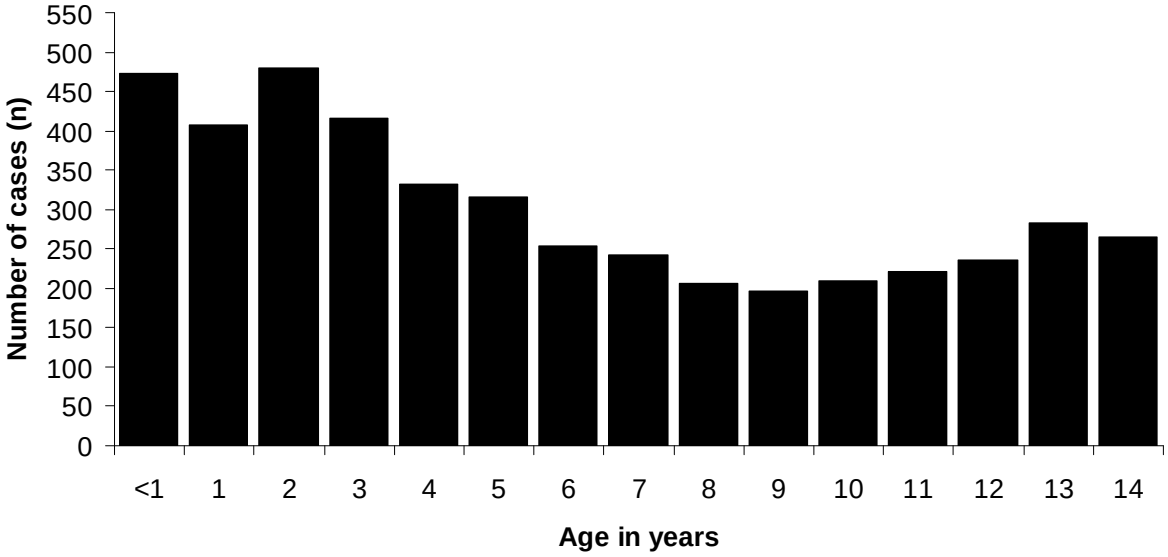


Figure 4 – Age at first diagnosis, by sex

(Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2007 (N=4539))

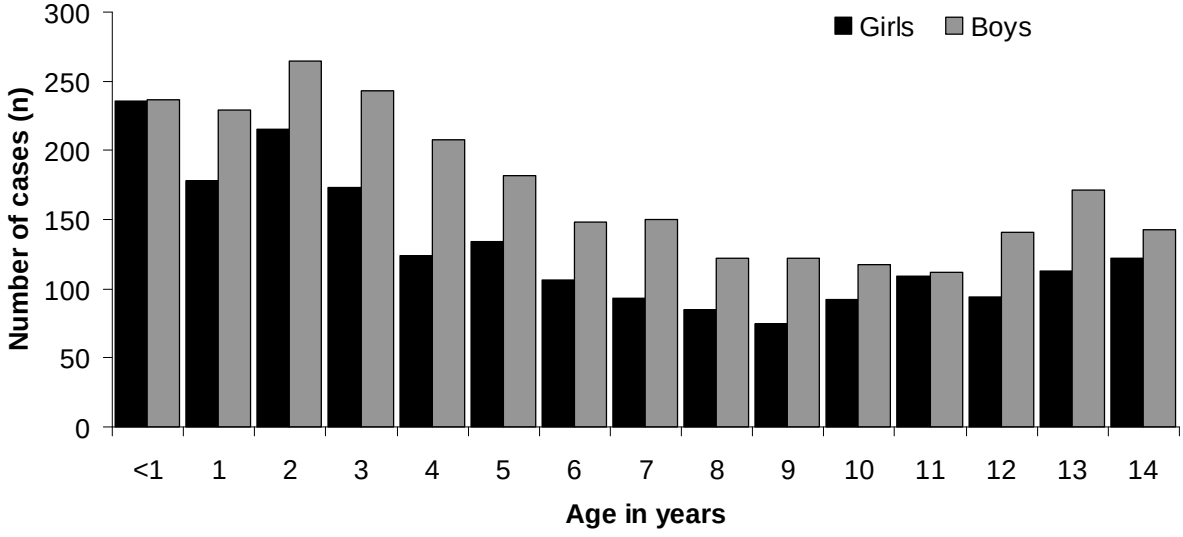


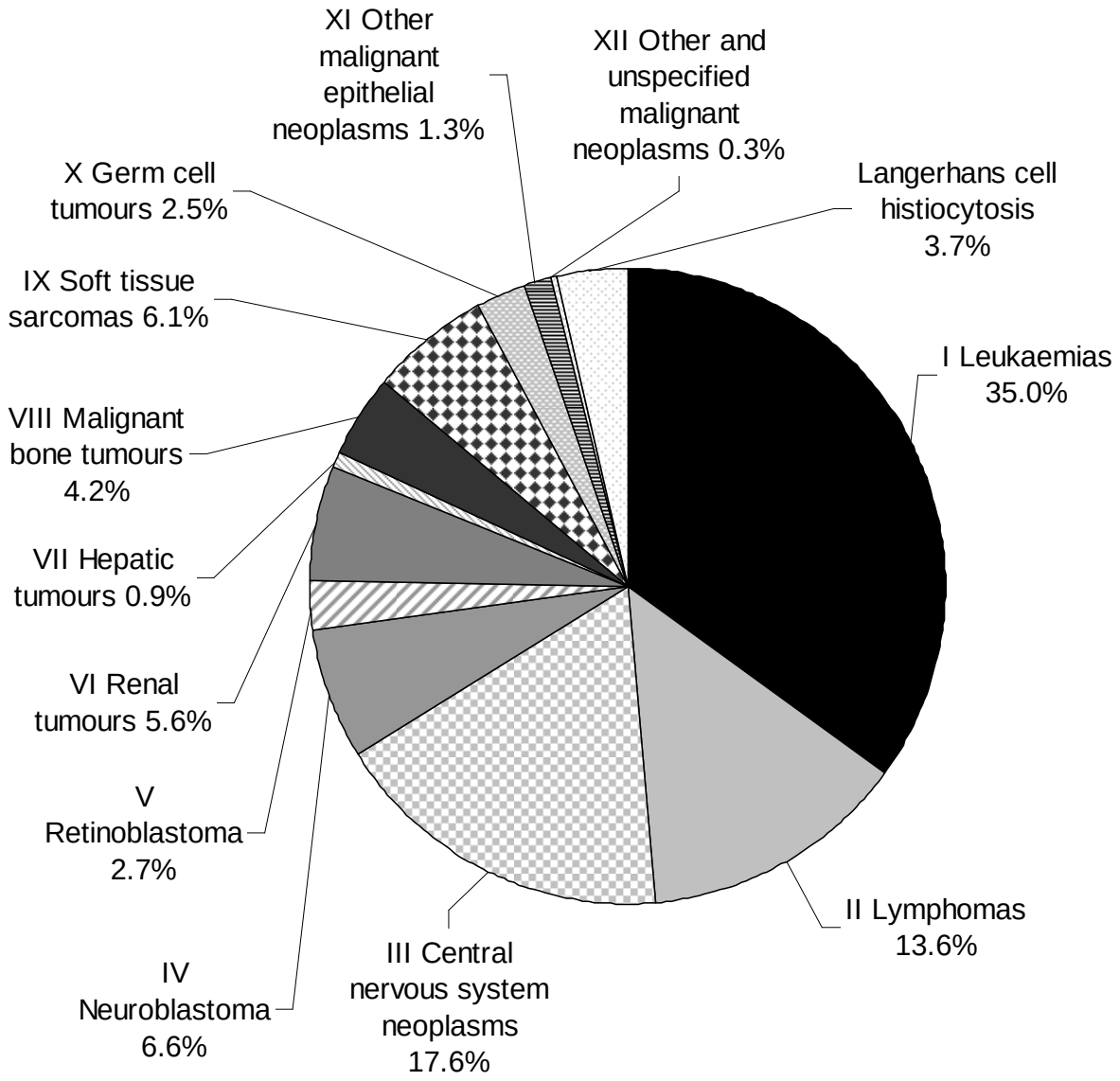
Table 5 – Diagnostic groups according to ICCC-3

(Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2007 (N=4539))

Diagnosis	Total n	Age group <1yr	1-4yrs	5-9yrs	10-14yrs
I Leukaemias, myeloproliferative diseases and myelodysplastic diseases	1588	60	763	448	317
II Lymphomas and reticuloendothelial neoplasms	618	16	93	182	327
III Central nervous system neoplasms	798	58	234	291	215
IV Neuroblastoma and other peripheral nervous cell tumours	298	135	125	26	12
V Retinoblastoma	121	57	55	8	1
VI Renal tumours	256	39	150	59	8
VII Hepatic tumours	42	13	15	5	9
VIII Malignant bone tumours	189	0	17	57	115
IX Soft tissue and other extraosseous sarcomas	275	31	78	73	93
X Germ cell tumours, trophoblastic tumours and neoplasms of gonads	112	22	28	14	48
XI Other malignant epithelial neoplasms and malignant melanomas	60	4	8	12	36
XII Other and unspecified malignant neoplasms	12	2	3	1	6
Langerhans cell histiocytosis	170	36	66	41	27
TOTAL	**4539**	**473**	**1635**	**1217**	**1214**

Figure 5 – Diagnostic groups according to ICCC-3

(Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2007 (N=4539))



Diagnosis according to ICCC-3 for all cases registered in the SCCR between 1998-2007

Table 6 reports detailed information on diagnosis according to ICCC-3 for all cases registered in the SCCR during the past 10 years (1998-2007). Relative frequency of the different diagnoses, sex ratio, mean age at diagnosis and age-standardised incidence are very similar to results from Germany.[6]

As found in other childhood cancer registries there were a higher number of boys than girls. This was true for most types of tumours with the exception of neuroblastoma, germ cell tumours and other malignant epithelial neoplasms.

The age-standardised incidence of any childhood cancer (not including Langerhans cell histiocytosis) in the past 5 years was 21.7 cases per 100,000 person/years in Switzerland (age-standardisation according to the world population for the age-groups under 15 years[7]). Age adjusted incidence was highest among children aged less than 1 year with 37.2 cases per 100,000 person/years and lowest in 9 year olds and older with 16.7 cases per 100,000 person/years (**Figure 6** showing crude incidence rates and **Figure 7** showing age- and sex-specific incidence rates).

[6] Kaatsch P, Spix C. Annual report 2008: German Childhood Cancer Registry (GCCR). Mainz; 2009

[7] Parkin DM, Kramarova E, Draper GJ, Masuyer E, Michaelis J, Neglia J, et al. The international incidence of childhood cancer, Vol II. Lyon: IARC Scientific Publications; 1998.

Table 6 – Number of registered cases in the SCCR, sex ratio, mean age at diagnosis and age-standardised incidence* (per 100,000 person/years), by diagnostic groups according to ICCC-3

(Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1998-2007 (N=1795))

		n	Relative %	Sex Ratio (M:F)	Mean age	Incidence*
I	**Leukaemias, myeloproliferative diseases and myelodysplastic diseases**	**565**	**32.6**	**1.4**	**4.8**	**46.5**
	a. Lymphoid leukaemias	459	81.2	1.3	4.6	37.7
	b. Acute myeloid leukaemias	73	12.9	1.6	5.4	6.0
	c. Chronic myeloproliferative diseases	4	0.7	3.0	9.2	0.3
	d. Myelodysplastic syndrome and other myeloproliferative diseases	19	3.4	1.1	8.8	1.6
	e. Unspecified and other specified leukaemias	10	1.8	1.5	3.5	0.8
II	**Lymphomas and reticuloendothelial neoplasms**	**212**	**12.2**	**1.9**	**10.3**	**17.4**
	a. Hodgkin lymphomas	88	41.5	1.1	12.7	7.2
	b. Non-Hodgkin lymphomas (except Burkitt lymphoma)	84	39.6	2.1	9.0	6.9
	c. Burkitt lymphoma	35	16.5	7.8	7.3	2.9
	d. Miscellaneous lymphoreticular neoplasms	4	1.9	3.0	0.9	0.3
	e. Unspecified lymphomas	1	0.5	0.0	13.6	0.1
III	**CNS and miscellaneous intracranial and intraspinal neoplasms**	**397**	**22.9**	**1.2**	**6.7**	**32.6**
	a. Ependymomas and choroid plexus tumour	30	7.6	0.9	2.1	2.5
	b. Astrocytomas	151	38.0	1.3	7.2	12.4
	c. Intracranial and intraspinal embryonal tumours	103	25.9	1.6	5.7	8.5
	d. Other gliomas	41	10.3	1.0	5.9	3.4
	e. Other specified intracranial and intraspinal neoplasms	67	16.9	0.9	9.7	5.5
	f. Unspecified intracranial and intraspinal neoplasms	5	1.3	0.7	9.5	0.4
IV	**Neuroblastoma and other peripheral nervous cell tumours**	**109**	**6.3**	**0.9**	**0.9**	**9.0**
	a. Neuroblastoma and ganglioneuroblastoma	109	100.0	0.9	0.9	9.0
V	**Retinoblastoma**	**41**	**2.4**	**1.0**	**0.9**	**3.4**
VI	**Renal tumours**	**97**	**5.6**	**1.2**	**2.9**	**8.0**
	a. Nephroblastoma and other nonepithelial renal tumours	94	96.9	1.3	2.8	7.7
	b. Renal carcinomas	2	2.1	0.0	13.7	0.2
	c. Unspecified malignant renal tumours	1	1.0	0.0	12.8	0.1

Table 6 – continued

		n	Relative %	Sex Ratio (M:F)	Mean age	Incidence*
VII	**Hepatic tumours**	**22**	**1.3**	**2.1**	**1.4**	**1.8**
	a. Hepatoblastoma	17	77.3	3.3	1.1	1.4
	b. Hepatic carcinomas	5	22.7	0.7	13.7	0.4
VIII	**Malignant bone tumours**	**92**	**5.3**	**0.9**	**10.9**	**7.6**
	a. Osteosarcomas	47	51.1	0.8	11.7	3.9
	c. Ewing tumour and related sarcomas of bone	45	48.9	1.0	10.6	3.7
IX	**Soft tissue and other extraosseous sarcomas**	**118**	**6.8**	**1.4**	**8.4**	**9.7**
	a. Rhabdomyosarcomas	73	61.9	2.0	5.8	6.0
	b. Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms	6	5.1	1.0	0.1	0.5
	d. Other specified soft tissue sarcomas	26	22.0	0.9	11.9	2.1
	e. Unspecified soft tissue sarcomas	13	11.0	0.6	7.9	1.1
X	**Germ cell tumours, trophoblastic tumours, and neoplasms of gonads**	**46**	**2.7**	**0.8**	**7.7**	**3.8**
	a. Intracranial and intraspinal germ cell tumours	10	21.7	2.3	9.5	0.8
	b. Malignant extracranial and extragonadal germ cell tumours	11	23.9	0.2	0.4	0.9
	c. Malignant gonadal germ cell tumours	23	50.0	0.9	10.3	1.9
	d. Gonadal carcinomas	2	4.3	1.0	13.0	0.2
XI	**Other malignant epithelial neoplasms and malignant melanomas**	**34**	**2.0**	**1.3**	**11.2**	**2.8**
	a. Adrenocortical carcinomas	2	5.9	1.0	4.2	0.2
	b. Thyroid carcinomas	10	29.4	1.5	12.6	0.8
	d. Malignant melanomas	13	38.2	0.6	6.5	1.1
	e. Skin carcinomas	2	5.9	0.0	7.2	0.2
	f. Other and unspecified carcinomas	7	20.6	2.5	11.1	0.6
XII	**Other and unspecified malignant neoplasms**	**1**	**0.1**	0.0	**12.9**	**0.1**
	a. Other specified malignant tumours	1	100.0	0.0	12.9	0.1
	Total (not including Langerhans cell histiocytosis)	**1734**	**100.0**	**1.3**	**6.6**	**142.6**
	Langerhans cell histiocytosis	**61**	**3.4**	**1.1**	**5.8**	**5.0**
	Total (including Langerhans cell histiocytosis)	**1795**	**100.0**	**1.3**	**5.7**	**147.6**

Figure 6 – Crude incidence rate (per 100,000 person/years) in Switzerland

(Swiss residents, aged 0-14 years at diagnosis, not including Langerhans cell histiocytosis, years of diagnosis 1990-2007 (N=3024))

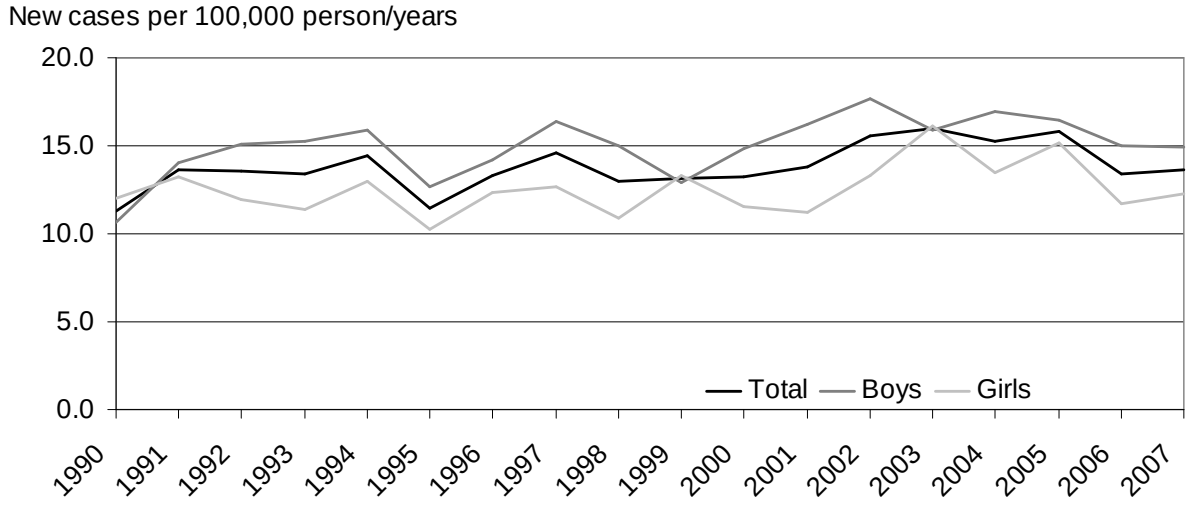


Figure 7 – Age- and sex-specific incidence rates (per 100,000 person/years) in Switzerland

(Swiss residents, aged 0-14 years at diagnosis, not including Langerhans cell histiocytosis, years of diagnosis 1998-2007 (N=1735))

3.3 Cases reported by the 9 centres of the SPOG

Tables 7 and 8 show the distribution of patients reported from the 9 SPOG clinics, for the periods 1976-1997 (**Table 7**) and 1998-2007 (**Table 8**) respectively. Table 9a and Table 9b show the numbers reported from the different SPOG clinics in the year 2006 (**Table 9a**) and 2007 (**Table 9b**) respectively.

All patients irrespective of age and residency (Swiss and foreign patients) are included in these tables.

Table 7 – Diagnosed* childhood cancer cases between 1976 and 1997, by participating oncology clinic

(including all age groups, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-1997 (N=3402))
All patients irrespective of age and residency (Swiss and foreign patients) are included in this analysis.

		Total		Aarau		Basel		Bern		Geneva		Lausanne		Locarno		Lucerne		StGallen		Zurich		Unknown‡	
	Diagnosis	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
I	Leukaemias	1161	100	81	7.0	114	9.8	302	26.0	99	8.5	120	10.3	19	1.6	91	7.8	120	10.3	203	17.5	12	1.0
II	Lymphomas	493	100	36	7.3	46	9.3	117	23.7	41	8.3	69	14.0	11	2.2	30	6.1	39	7.9	92	18.7	12	2.4
III	Central nervous system neoplasms	495	100	27	5.5	34	6.9	170	34.3	43	8.7	60	12.1	10	2.0	10	2.0	38	7.7	83	16.8	20	4.0
IV	Neuroblastoma	232	100	7	3.0	22	9.5	44	19.0	24	10.3	39	16.8	0	0.0	17	7.3	18	7.8	56	24.1	5	2.2
V	Retinoblastoma†	172	100	0	0.0	7	4.1	17	9.9	16	9.3	103	59.9	2	1.2	8	4.7	9	5.2	8	4.7	2	1.2
VI	Renal tumours	183	100	5	2.7	16	8.7	43	23.5	14	7.7	23	12.6	0	0.0	18	9.8	17	9.3	46	25.1	1	0.5
VII	Hepatic tumours	28	100	0	0.0	2	7.1	10	35.7	2	7.1	4	14.3	0	0.0	0	0.0	1	3.6	9	32.1	0	0.0
VIII	Malignant bone tumours	179	100	6	3.4	27	15.1	52	29.1	23	12.8	29	16.2	2	1.1	6	3.4	13	7.3	15	8.4	6	3.4
IX	Soft tissue sarcomas	197	100	7	3.6	17	8.6	49	24.9	12	6.1	32	16.2	3	1.5	17	8.6	22	11.2	32	16.2	6	3.0
X	Germ cell tumours	98	100	7	7.1	8	8.2	23	23.5	10	10.2	13	13.3	2	2.0	2	2.0	5	5.1	26	26.5	2	2.0
XI	Other malignant epithelial neoplasms	34	100	1	2.9	2	5.9	10	29.4	5	14.7	7	20.6	1	2.9	1	2.9	1	2.9	3	8.8	3	8.8
XII	Other and unspecified malignant neoplasms	12	100	0	0.0	1	8.3	2	16.7	0	0.0	3	25.0	0	0.0	0	0.0	0	0.0	1	8.3	5	41.7
	Langerhans cell histiocytosis	118	100	6	5.1	14	11.9	30	25.4	4	3.4	14	11.9	1	0.8	8	6.8	21	17.8	20	16.9	0	0.0
	TOTAL	3402	100	183	5.4	310	9.1	869	25.5	293	8.6	516	15.2	51	1.5	208	6.1	304	8.9	594	17.5	74	2.2

* Diagnosis coded according to ICCC-3

† Most cases with retinoblastoma are treated at the specialised Jules Gonin Eye Hospital at the University Hospital in Lausanne

‡ Treating institution unknown

Table 8 – Diagnosed* childhood cancer cases between 1998 and 2007, by participating oncology clinic

(including all age groups, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1998-2007 (N=2146))
All patients irrespective of age and residency (Swiss and foreign patients) are included in this analysis.

		Total		Aarau		Basel		Bern		Geneva		Lausanne		Locarno		Lucerne		StGallen		Zurich		Unknown‡	
	Diagnosis	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
I	Leukaemias	640	100	45	7.0	49	7.7	111	17.3	44	6.9	89	13.9	16	2.5	43	6.7	69	10.8	166	25.9	8	1.3
II	Lymphomas	273	100	18	6.6	20	7.3	49	17.9	19	7.0	46	16.8	7	2.6	32	11.7	25	9.2	52	19.0	5	1.8
III	Central nervous system neoplasms	451	100	23	5.1	26	5.8	90	20.0	33	7.3	85	18.8	13	2.9	4	0.9	37	8.2	125	27.7	15	3.3
IV	Neuroblastoma	122	100	5	4.1	14	11.5	16	13.1	8	6.6	23	18.9	1	0.8	9	7.4	12	9.8	34	27.9	0	0.0
V	Retinoblastoma†	105	100	0	0.0	4	3.8	3	2.9	2	1.9	85	81.0	0	0.0	2	1.9	2	1.9	5	4.8	2	1.9
VI	Renal tumours	103	100	9	8.7	11	10.7	16	15.5	11	10.7	10	9.7	4	3.9	5	4.9	10	9.7	27	26.2	0	0.0
VII	Hepatic tumours	25	100	4	16.0	2	8.0	3	12.0	2	8.0	3	12.0	2	8.0	0	0.0	3	12.0	5	20.0	1	4.0
VIII	Malignant bone tumours	125	100	5	4.0	22	17.6	17	13.6	15	12.0	28	22.4	3	2.4	3	2.4	8	6.4	22	17.6	2	1.6
IX	Soft tissue sarcomas	141	100	13	9.2	13	9.2	21	14.9	12	8.5	23	16.3	2	1.4	12	8.5	10	7.1	30	21.3	5	3.5
X	Germ cell tumours	54	100	7	13.0	3	5.6	5	9.3	5	9.3	12	22.2	1	1.9	6	11.1	5	9.3	7	13.0	3	5.6
XI	Other malignant epithelial neoplasms	44	100	3	6.8	4	9.1	4	9.1	2	4.5	3	6.8	1	2.3	4	9.1	7	15.9	8	18.2	8	18.2
XII	Other and unspecified malignant neoplasms	3	100	0	0.0	0	0.0	1	33.3	1	33.3	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	33.3
	Langerhans cell histiocytosis	60	100	5	8.3	5	8.3	12	20.0	2	3.3	12	20.0	3	5.0	2	3.3	7	11.7	12	20.0	0	0.0
	TOTAL	2146	100	137	6.4	173	8.1	348	16.2	156	7.3	419	19.5	53	2.5	122	5.7	195	9.1	493	23.0	50	2.3

* Diagnosis coded according to ICCC-3

† Most cases with retinoblastoma are treated at the specialised Jules Gonin Eye Hospital at the University Hospital in Lausanne

‡ Treating institution unknown

Table 9a – Diagnosed* childhood cancer cases in 2006, by participating oncology clinic

(including all age groups, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), new patients diagnosed in 2006 (N=215))
All patients irrespective of age and residency (Swiss and foreign patients) are included in this analysis.

	Diagnosis	Total	Aarau	Basel	Bern	Geneva	Lausanne	Locarno	Lucerne	StGallen	Zurich	Unknown‡
I	Leukaemias	55	6	3	11	1	6	1	5	8	13	1
II	Lymphomas	35	5	4	8	2	5	2	2	2	3	2
III	Central nervous system neoplasms	41	0	1	9	1	10	1	1	3	15	0
IV	Neuroblastoma	14	0	2	1	1	4	0	2	0	4	0
V	Retinoblastoma†	11	0	0	0	0	8	0	1	0	0	2
VI	Renal tumours	14	1	1	2	1	0	0	1	1	7	0
VII	Hepatic tumours	1	0	0	0	1	0	0	0	0	0	0
VIII	Malignant bone tumours	12	0	1	1	2	3	1	0	1	2	1
IX	Soft tissue sarcomas	16	2	1	3	4	1	1	2	1	1	0
X	Germ cell tumours	6	1	2	0	0	0	0	1	1	1	0
XI	Other malignant epithelial neoplasms	5	0	0	0	0	1	0	0	2	1	1
XII	Other and unspecified malignant neoplasms	1	0	0	1	0	0	0	0	0	0	0
	Langerhans cell histiocytosis	4	1	0	2	0	1	0	0	0	0	0
	TOTAL	**215**	**16**	**15**	**38**	**13**	**39**	**6**	**15**	**19**	**47**	**7**

* Diagnosis coded according to ICCC-3

† Most cases with retinoblastoma are treated at the specialised Jules Gonin Eye Hospital at the University Hospital in Lausanne

‡ Treating institution unknown

Table 9b – Diagnosed* childhood cancer cases in 2007, by participating oncology clinic

(including all age groups, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), new patients diagnosed in 2007 (N=199))
All patients irrespective of age and residency (Swiss and foreign patients) are included in this analysis.

	Diagnosis	Total	Aarau	Basel	Bern	Geneva	Lausanne	Locarno	Lucerne	St. Gallen	Zurich	Unknown‡
I	Leukaemias	73	3	6	12	5	15	1	5	9	16	1
II	Lymphomas	31	4	3	6	0	5	0	6	3	3	1
III	Central nervous system neoplasms	35	2	2	5	1	12	0	0	0	11	2
IV	Neuroblastoma	12	1	1	3	1	0	0	0	2	4	0
V	Retinoblastoma†	9	0	0	0	0	9	0	0	0	0	0
VI	Renal tumours	6	1	1	1	0	0	0	0	1	2	0
VII	Hepatic tumours	1	0	0	0	0	0	0	0	0	1	0
VIII	Malignant bone tumours	8	0	1	0	0	4	0	0	0	3	0
IX	Soft tissue sarcomas	10	0	1	1	0	2	0	1	2	2	1
X	Germ cell tumours	3	0	0	0	0	2	0	0	0	1	0
XI	Other malignant epithelial neoplasms											
XII	Other and unspecified malignant neoplasms	4	0	0	0	1	0	0	1	1	1	0
	Langerhans cell histiocytosis	7	1	1	0	0	2	0	0	3	0	0
	TOTAL	**199**	**12**	**16**	**28**	**8**	**51**	**1**	**13**	**21**	**44**	**5**

* Diagnosis coded according to ICCC-3

† Most cases with retinoblastomas are treated at the specialised Jules Gonin Eye Hospital at the University Hospital in Lausanne

‡ Treating institution unknown

4 Current research projects at the SCCR

The section on current research projects at the SCCR includes two chapters.

Chapter 4.1 lists studies conducted in one or several centres of the Swiss Paediatric Oncology Group, to which the SCCR contributed data or performed statistical analyses.

Chapter 4.2 describes past or current research projects, which are conducted at the SCCR.

4.1 Collaboration in research projects of the SPOG

This concerns projects initiated and led by members of the Swiss Paediatric Oncology Group (single centre and multi centre projects, MD theses and PhD theses) where the SCCR contributed, by extracting data from the SCCR database or participating in data analysis and interpretation.

Table 10 includes a list of these projects since 2005 with related publications.

4.2 Research projects conducted at the SCCR

This relates to research projects which are initiated and conducted by the SCCR, using mainly data from the SCCR, newly collected data and often comparison data from other national datasets (such as the Swiss National Cohort or the Swiss Health Surveys).
Table 11 lists all research projects conducted at the SCCR since 2005, finished projects as well as ongoing projects. Subsequently, some are described in more detail. Additional information is available from the references and from the investigators. We thank all sponsors of the projects.

Table 10 – Collaboration in studies conducted by Swiss Paediatric Oncology Group since 2005

No	Title	Investigator	Population	Data extracted	Date of extraction	Publications
1	Survival of childhood cancer in the past 30 years in Zurich	F. Niggli, Zurich	All patients from Zurich with follow-up information (N=650)	Diagnosis, age, sex, date of diagnosis, death and last follow-up. Cox regression and Kaplan Meyer curves	Mar 05	Oral presentation, University Children's Hospital, Zurich
2	Retinoblastoma treatment in Switzerland	M. Beck-Popovic, Lausanne	All patients with retinoblastoma who were registered in the SCCR (n=245)	Year of diagnosis, treating institutions	Aug 05	Wallach M. et al.: Shorter time to diagnosis and improved stage at presentation in Swiss patients with retinoblastoma treated from 1963 to 2004. Pediatrics 2006;118:e1493-8.
3	Number of patients with Ewing sarcoma of Rhabdomyosarcoma	M. Paulussen, Basel	All patients with Ewing sarcoma or rhabdmyosarcoma diagnosed from 2000 to 2004	Diagnosis, year of diagnosis	Dec 05	Kreuter M. et al.: Clinical significance of Vascular Endothelial Growth Factor-A expression in Ewing's sarcoma. Eur J Cancer 2006;42:1904-11.
4	Leukaemia in Switzerland	J-P. Bourquin, Lausanne	All leukaemia cases in Switzerland since 1994 (N=811)	Diagnosis, year of diagnosis, sex	Jun 06	Oral presentations
5	Renal tumours in Switzerland	M. Diezi, Lausanne	All patients with renal tumours registered in the SCCR from 1992-2004 (N=145)	Diagnosis, date of birth and diagnosis, age at diagnosis, annual incidence	Oct 06	Diezi M. et al.: Renal tumours in children. Rev Med Suisse 2007;3:360-2, 364-5. French
6	Craniopharyngeoma patients in Bern	M. Janner, Bern	All patients with a craniopharyngeoma from Bern (N=17)	Names, dates of birth and diagnosis, sex	Jan 07	Presentation internal meeting, University Children's Hospital, Bern

Table 10 – continued

No	Title	Investigator	Population	Data extracted	Date of extraction	Publications
7	Childhood acute myeloid leukaemias (AML): the clinical significance of cytogenetic events at presentation and relapse	D. Betts, Zurich	All patients with AML registered in the SCCR (N=103)	All information on patient, tumour and therapy levels. Calculation of survival.	Feb 07	Betts DR. et al.: The prognostic significance of cytogenetic aberrations in childhood acute myeloid leukaemia. A study of the Swiss Paediatric Oncology Group (SPOG); Eur J Haematol. 2007;78:468-76.
8	Wilms Tumour, Soft tissue sarcoma (STS) and autologous bone marrow transplantation (BMT)	N. von der Weid, Lausanne	All patients with Wilms tumour of STS who had autologous bone marrow transplantation	Diagnosis, year of diagnosis, autologous BMT	May 07	Retrospective request of EBMT registry
9	Patients with diagnosis date between 01.11.06–31.10.07	N. von der Weid, Lausanne		Diagnosis, year of diagnosis, year of relapse	Feb 08	Annual report SPOG
10	Medulloblastoma and trisomy 21	N. von der Weid, Lausanne	All patient with medulloblastoma and prior relevant diseases (trisomy 21)	Diagnosis and prior relevant diseases	Nov 08	Publication in preparation (international collaboration)
11	Primitive neuroectodermal tumour (PNET) and trisomy 21	N. von der Weid, Lausanne	All patient with PNET and prior relevant diseases (trisomy 21)	Diagnosis and prior relevant diseases	Dec 08	Publication in preparation (international collaboration)
12	Patients with diagnosis date between 01.11.07–31.10.08	N. von der Weid, Lausanne		Diagnosis, year of diagnosis, year of relapse	Feb 09	Annual report SPOG
13	Current address research for patients from cerebral tumour database Zurich	M. Grotzer, Zurich	Address from patients with cerebral tumour	Current addresses	Mar 09	Project ongoing

Table 11 – Research projects of the SCCR since 2005

No	Project name	Funding	Primary investigator	Study Type	Study period
1	Follow-up care after childhood and young adult cancer	Swiss National Science Foundation	Michel G	Cohort study	08.2009-07.2012
2	Childhood Cancer and Nuclear Power Plants in Switzerland - CANUPIS	Swiss Federal Office of Health / Swiss Cancer League	Kuehni CE	Cohort study	09.2008-03.2011
3	Swiss Childhood Cancer Survivor Study (SCCSS)	Oncosuisse	von der Weid NX Kuehni CE	Cohort study	01.2006-08.2010
4	Childhood leukaemia and lymphoma: are incidence and survival in Switzerland associated with socio-economic status?	Oncosuisse	Zwahlen M	Cohort study	08.2007-07.2009
5	An international case-control study on brain tumours in children and adolescents - CEFALO	Swiss Research Foundation on Mobile Communication / Swiss Federal Office of Health	Roeoesli M	Cohort study	10.2005-12.2008
6	Completeness of cancer registration and diagnostic accuracy in the Swiss Childhood Cancer Registry: validation against independent sources of data	Bernese Cancer League	Egger M	Cohort study	06.2006-08.2007
7	Validating date and cause of death information in the SCCR against death certificate information from the Swiss Federal Statistical Office	Swiss Federal Statistical Office	Kuehni CE	Cohort study	2005

Project 1 - Follow-up care after childhood and young adult cancer

This is a survey of long-term survivors (≥ 5 years) of childhood cancer, oncologists, haematologists and family practitioners in Switzerland, to assess current use of follow-up care and preferences/opinions for a future Swiss model of follow-up care.

Background: Treatment for cancer in children and young adults has greatly improved and most patients are being cured. However, more than 50% of survivors of childhood cancer suffer from late effects. To detect and treat late effects as early as possible it is important that survivors continue to visit follow-up care long after they have been cured from the cancer. Various models of follow-up care have been described but so far none has been implemented in Switzerland. While follow-up care needs to be constantly updated according to the current status of research, it is also important that it is convenient for survivors to participate.

Aims: 1) Compare advantages and disadvantages of follow-up care models currently used in Europe. 2) Determine the current availability and use of follow-up care in survivors of childhood and young adult cancer in Switzerland. 3) Determine the advantages and disadvantages of follow-up care models as perceived by survivors, oncologists and family practitioners, and compare their views and opinions.

Methods: Part 1 will comprise a questionnaire survey of clinics and follow-up programs to assess the models of care currently used in Europe. In part 2, current use of follow-up care together with their psychological well-being will be determined in childhood cancer survivors using data from the Swiss Childhood Cancer Survivor Study. In part 3, a questionnaire survey will assess opinions and perspectives on currently used and desired optimal follow-up care. The sample will include cancer survivors who were diagnosed with cancer between 1990 and 2005 and aged under 25 years, who have survived for more than 5 years and who are currently aged 11 years and older. In addition paediatric and adult oncologists and haematologists, and family practitioners will fill in a questionnaire.

Rationale and significance: This project will give an overview of follow-up care models used in Europe and describe the preferences for follow-up care models in survivors, oncologists and family practitioners in Switzerland. Differences between the three groups will be determined in order to improve follow-up care in the future, adapting it to the differing preferences. The project will provide the basis for the development of a standardised model of follow-up care for childhood cancer survivors in Switzerland.

Study Team

Applicant: Michel G. Institute of Social and Preventive Medicine, University of Bern. **Project team**: Michel G, Kuehni CE, Egger M, Viehmann G. Institute of Social and Preventive Medicine, University of Bern; Von der Weid N. Paediatric Oncology, CHUV Lausanne; Niggli F. University Children's Hospital, Zurich.

Collaborations

Skinner R, Kremer L, Frey E, Levitt G, Bardi E. PANCARE (European collaboration on follow-up care after childhood cancer); Eiser C, Greenfield D. Child and Family Research Group, University of Sheffield.

Publications expected for 2011.

Project 2 - Childhood Cancer and Nuclear Power Plants in Switzerland - CANUPIS

This study addresses the question if residence in the proximity of a nuclear power plant (NPP) is associated with an increased risk of childhood cancer, and whether this can be explained by confounding, particularly by other area-based risk factors for childhood cancer which might cluster around nuclear power plants. Details are available from the dedicated CANUPIS-Homepage: www.canupis.ch

Background: Since the reporting of a cluster of leukaemia cases around Sellafield in 1984, numerous studies have assessed the risk of childhood cancer and residence in the proximity of nuclear power plants (NPPs). These studies showed heterogeneous results, many with weak positive associations. An explanation for this excess is lacking. Emissions from NPPs during normal operation are low in comparison to the annual background exposure and dose-response studies do not support a causal association. A recent case-control study from Germany, showing a small but statistically significant increase in the risk of cancer, particularly leukaemia, in children aged less than five years living near NPPs refuelled the public discussion about this potential hazard. The study, as many others, had methodological problems limiting the interpretability of the results, including i) a potential selection bias because of differential response rates of municipalities; ii) possible bias due to selection of controls by local clerks; iii) lack of adjustment for potential confounding factors such as electric power lines, major roads, socio-economic status, and other factors; and iv) analysis of residency at the time of cancer diagnosis only (because of the known latency in development of malignant diseases, the place of residence prior to the diagnosis is of great interest).

Aims: To investigate whether living near a NPP increases the risk of childhood cancer in general, and childhood leukaemia in particular.

Methods: This is a census-based cohort study with national coverage. Selection bias is minimized by using geocoded addresses for each child, important potential confounders will be adjusted for, and residential history back to the date of birth will be included. The study uses the Swiss National Cohort (SNC), a long-term, census-based, multipurpose cohort and research platform including all Swiss inhabitants (6.8 million people) to estimate person-years at risk. Cases are identified via the Swiss Childhood Cancer Registry (SCCR). Included are all patients born between Jan 1985 and Dec 2007, aged less than16 years at diagnosis and resident in Switzerland.

Our main exposure is proximity to nuclear sites modelled as four categories (the inner 5 km zone, 5-10 km, 10-15 km and more than15 km). The following confounders are included: Distance to major roads, electric power lines and broadcast transmitters, natural ionising radiation, area statistics (e.g. pesticides from agriculture or golf courses), pollutants from industry, degree of urbanisation, socio-economic status (using the Sotomo-Index) and average number of children per family at communal level.

Rational and significance: This study will add importantly to the current evidence base on the risk of childhood cancer and residence in the proximity of nuclear sites. It will overcome important methodological problems of previous studies. Given the fact that additional nuclear sites are currently planned in Switzerland, the topic is of high public health and policy relevance.

Study Team

Applicants: Von der Weid N. Paediatric Oncology, CHUV Lausanne; Niggli F. University Children's Hospital, Zurich; Hengartner H. Ostschweizer Kinderspital, St. Gallen; Egger M. Institute of Social and Preventive Medicine, University of Bern. **Project team**: Feller M, Kuehni CE, Güler A, Viehmann G, Spring-Rüesch M, Röösli M, Huss A. Institute of Social and Preventive Medicine, University of Bern

Publications expected for 2011.

Project 3 - Swiss Childhood Cancer Survivor Study (SCCSS)

This is a follow-up survey of all long-term survivors (≥ 5 years after diagnosis) of childhood cancer in Switzerland, to assess somatic and psychosocial late effects and health-related quality of life.

Background: Thanks to therapeutic improvements in the past decades, survival rates in childhood cancer have increased to 75-80%, resulting in a growing population of long-term survivors. However, cancer and cancer treatments have been associated with adverse late effects. Therefore, health and quality of life of survivors are a matter of increasing concern. In Switzerland and elsewhere, comprehensive data on the burden of late effects of childhood cancer and its risk factors, and data on use of follow-up care in long-term survivors are scarce.

Aims: This project investigates the long-term outcome of former childhood cancer patients who were diagnosed with cancer before age 16 and survived for more than 5 years. It studies incidence of various somatic outcomes (late mortality, secondary malignancies, endocrine disorders, infertility, cardiovascular events) and health related quality of life (HRQoL), and their association with a number of risk factors assessed prospectively at the time of diagnosis (tumour, treatment modalities, demographic characteristics). In addition, current practice of health-care provision and health behaviour in long-term survivors are investigated.

Methods: This is a prospective cohort study based on the population of children registered in the Swiss Childhood Cancer Registry (SCCR). The SCCR contains 5866 records on childhood cancer patients (Sep 2008). Eligible for the study are 2900 individuals, who have been diagnosed before May 1, 2003 (i.e. at least 5 years prior to beginning of the study) have survived for more than 5 years and are Swiss residents. The age range at the time of the study is 5 to 49 years.

A detailed questionnaire is being sent to all participants, assessing demographic and socio-economic information, educational and professional achievements, current medical conditions and treatments, HRQoL, health behaviour and healthcare provision. Sub-samples of participants from the major diagnostic groups reporting potentially relevant events will be interviewed in more detail by phone. If consent is given, questionnaire data will be complemented with and validated against general practitioners and hospital records.

Rationale and significance: The existing database of the SCCR gives the rare opportunity for a nationwide study of long-term outcomes in survivors of childhood cancer. The project will increase the knowledge on incidence and risk factors of late effects and provide a summary of the current status of care in Switzerland. As many late effects can be prevented or cured if diagnosed early, this study will also contribute to improving the health of current and future survivors of childhood cancer.

Study team

Applicants: Von der Weid N. Paediatric Oncology, CHUV Lausanne; Kuehni CE, Egger M, Zwahlen M. Institute of Social and Preventive Medicine, University of Bern; Probst-Hensch N. Dept. of Pathologie / Dept. of Social and Preventive Medicine, University Hospital, Zurich; Niggli F. University Children's Hospital, Zurich. **Project team**: Rebholz C, Rueegg C, Plym A, Kuehni CE, Michel G. Institute of Social and Preventive Medicine, University of Bern; Von der Weid N. Paediatric Oncology, CHUV Lausanne; Niggli F. University Children's Hospital, Zurich

Publications

Original peer-reviewed papers

Michel G, Rebholz CE, von der Weid NX, Bergstraesser E, Kuehni CE. Psychological distress in adult survivors of childhood cancer: the Swiss Childhood Cancer Survivor Study. *submitted.*

Published abstracts

Essig S, Rebholz CE, Strippoli MPF, Michel G, Von der Weid NX, Niggli FK, Kuehni CE. Long-term childhood ALL survivors: Health-related quality of life after a relapse. *Swiss Med Wkly 2009*

Rueegg CS, Rebholz CE, Strippoli MPF, Michel G, Von der Weid NX, Niggli FK, Kuehni CE. Physical activity levels among Swiss childhood cancer survivors. *Swiss Med Wkly 2009*

Rebholz CE, von der Weid NX, Michel G, Niggli FK, Kuehni CE. Follow-up care in long-term childhood cancer survivors in Switzerland: who is missed out? *Swiss Med Wkly 2008;138(Suppl.164):4S*

Kuehni CE, Rebholz CE, Michel G, Adam M, Niggli FK, von der Weid NX. Educational level and employment of Swiss childhood cancer survivors, *Swiss Med Wkly 2008;138(Suppl.164):26S*

Rebholz CE, Von Der Weid NX, Michel G, Niggli FK, Kuehni CE. Smoking behaviour among Swiss childhood cancer survivors, *Swiss Med Wkly 2008;138(Suppl 164):26S*

Michel G, Rebholz CE, von der Weid NX, Bergstraesser E, Kuehni CE. Psychological distress in long-term survivors of childhood cancer in Switzerland. *Psychology and Health 2008;23(S1):184*

Rebholz CE, Kuehni CE, Michel G, von der Weid NX. The Swiss Childhood Cancer Survivor Study: Aims, methods and preliminary results. *Swiss Med Wkly 2007;137(Suppl. 158):6S*

Project 4 - Childhood leukaemia and lymphoma: are incidence and survival in Switzerland associated with socio-economic status?

The research project aims to investigate the association of socio-economic status (SES) with the risk of developing childhood leukaemia or childhood lymphoma, and to explore whether the association is varying with the operational definition of socio-economic status.

Aims: 1) To investigate the association of socio-economic status with the risk of developing childhood leukaemia or childhood lymphoma, and to explore whether the association is varying with the operational definition of socio-economic status. 2) To investigate the association of socio-economic status with the five-year survival rate for cases of childhood leukaemia or childhood lymphoma.

Methods: The two main aims are addressed by a case-control study design (for the association between SES and risk of disease) and by a prospective cohort study design of the included cases (for the differentials in mortality and survival). The study includes all cases of childhood leukaemia or lymphoma reported to the SCCR and diagnosed between 1991 and 2006 with a year of birth such that the diseased child has been recorded either in the 1990 or in the year 2000 census (approximately 700 leukaemia and 300 lymphoma cases). The restriction on being recorded in one of the censuses is needed to use the census information on profession and education of the child's parents thus obtaining relevant information on SES. Furthermore we are using information about the living conditions (number of rooms per person in the household, ownership of house or apartment) from the census data. Additionally, we use recently developed (Sotomo-Index, www.sotomo.geo.unizh.ch) area-based SES measures that are defined by the community in which a person lives. To obtain the SES information from the census records we have developed methodologically sound probabilistic record linkage procedures that relate the cancer cases and the census records of all residents in Switzerland. For the case-control study we have selected for each case 10 control children from the two census rounds. We thus can include approximately 1000 cases and 10,000 control subjects in the case-control part of the study. Analysis is being performed by logistic regression and time-to-event analyses (life-table, Kaplan-Meier estimates and proportional hazards models).

Rationale and significance: Childhood leukaemia and childhood lymphoma comprise about half of all cancer diagnoses in children. Therefore, assessing SES as a risk factor for this subgroup is of public health importance. Using the population-based childhood cancer registry in this study is unlikely to be hampered by biases involved in studying only selected subsets of cases.

Study team

Applicants: Zwahlen M, Egger M, Kuehni CE. Institute of Social and Preventive Medicine, University of Bern; Von der Weid N. Paediatric Oncology, CHUV Lausanne. **Project team**: Adam M, Zwahlen M, Kuehni CE, Spörri A, Schmidlin K. Institute of Social and Preventive Medicine, University of Bern

Publications

Original peer-reviewed papers

Adam M, Rebholz CE, Egger M, Zwahlen M, Kuehni CE. Childhood leukemia and socioeconomic status: what is the evidence? *Radiat Prot Dosim 2009;132:246-54.*

Project 5 - An international case-control study on brain tumours in children and adolescents – CEFALO

Background: It has been hypothesized that children could be more vulnerable to radio frequency electromagnetic field exposures from mobile telephones than adults, but no epidemiological studies of the relationship have been performed so far. The lack of knowledge causes conflicting recommendations from decision-makers, leading to anxiety and insecurity in the population. WHO has put a case-control study on childhood brain tumours as high priority on their 2006 research agenda on radio frequency electromagnetic fields.

Objectives: The main goal of the study is to investigate whether use of mobile telephones increases the risk of developing brain tumours for children or adolescents. In addition, our study will provide a comprehensive dataset to investigate other potential risk factors for childhood brain tumour.

Study design: The questions under study are being investigated by means of a case-control study in Denmark, Norway, Sweden and Switzerland. Cases were identified through a combination of registry data and information from the wards treating the patients (e.g. Swiss Paediatric Oncology Group). All incident cases of brain tumour in the age group 7-19 years between May 2004 and Apr 2008 were invited to participate. In total, the study is expected to include 550 cases of brain tumours in the participating countries, thereof 100 originating from Switzerland. For each case, two control persons have been randomly selected from the general population, matched on age, sex and geographic regions.

Exposure assessment: Information on the extent of exposure to radio frequency fields from mobile phones and on other known and suspected risk factors for childhood brain tumours is obtained by means of computer assisted personal interviews conducted by an interviewer trained for this purpose. The interviews took place either at the hospital or at the study participant's home. Objective information on the frequency and duration of mobile phone use is being obtained from mobile phone operators and from the information stored in the telephone that is in current use.

Data analyses: The data are being analyzed using established statistical methods for case-control studies, primarily via logistic regression models adjusted for potential confounding factors. In order to investigate potential gene-environment interactions, DNA from saliva samples is being extracted and analysed. Polymorphisms in genes that affect oxidative metabolism, detoxification of carcinogens, DNA stability and repair, or immune response, are candidates that might confer genetic susceptibility to brain tumours.

Study team

Applicants: Röösli M, Kuehni CE. Institute of Social and Preventive Medicine, University of Bern; Grotzer M. University Children's Hospital, Zurich; Feychting M. Karolinska Institute, Stockholm; Tynes T. Cancer Registry of Norway, Oslo; Von der Weid N. Paediatric Oncology, CHUV Lausanne; Schütz J. Institute of Cancer Epidemiology, University of Bielefeld. **Project Team**: Aydin D, Röösli M, Jenni D, Rey D. Institute of Social and Preventive Medicine, University of Basel; Kuehni CE, Michel G. Institute of Social and Preventive Medicine, University of Bern.

Publications

Original peer-reviewed papers

Kheifets L, Repacholi M, Saunders R, van Deventer E. The sensitivity of children to electromagnetic fields. *Pediatrics 2005;116(2): e303-13*

Published abstracts

Feychting M for the CEFALO Study Group. A case-control study of brain tumours in children and adolescents and mobile phone use. Symposium at the Joint Conference of the International Society for Environmental Epidemiology (ISEE) and the International Society for Exposure Assessment (ISEA), Sep 2-6, 2006, Paris. *Epidemiology 2006;17(6):S74.*

Conference or workshop abstracts

Schüz, J, Feychting, M, Röösli M, Tynes T, Samsø Schmidt L, Johansen C, Prohazka M, Sverin E, Jenni D, Kuehni CE, Klaboe L. An international case-control study on mobile phone use and the risk of brain tumours in children and adolescents (Cefalo study): a report from the field work and first results on mobile phone usage among children. 8th International Congress of the European Bioelectromagnetics Association (EBEA), Bordeaux 10-13 Apr 2007.

Röösli M for the CEFALO Study Group. An international case-control study on mobile phone use and the risk of brain tumours in children and adolescents (Cefalo study): study design and first experiences from the field work. Scientific Workshop hosted by the FGF: Do Children Represent a Special Sensitive Group for EMF-Exposure? - State of Research. Stuttgart, 27-29 Nov 2006. (www.cost281.org)

Other publications

Röösli M. Ursachen von Hirntumouren bei Kindern und Jugendlichen. Jahresbericht 2006 der Forschungsstiftung Mobilkommunikation; p. 22-23.
(http://www.mobile-research.ethz.ch/var/jb2006.pdf)

Project 6 - Completeness of cancer registration and diagnostic accuracy in the Swiss Childhood Cancer Registry: validation against independent sources of data

The research project has validated and compared patient records in the SCCR against data registered in cantonal cancer registries in Switzerland.

Aims: This research project aimed to validate and complete records of the SCCR against independent sources of data, particularly cantonal registries of the Association of Swiss Cancer Registries (ASRT). Particularly, we aimed to determine what proportion of childhood cancer patients was not treated in a Swiss Paediatric Cancer Centre (PCC), to describe the characteristics of these patients and to find out where they had been cared for.

Methods: The Swiss Childhood Cancer Registry (SCCR) registers all children treated in Swiss PCCs. The cantonal (=regional) cancer registries (existing in 14/26 cantons) register all cancer patients of a canton. We compared the children of both registries, using specialized software for record linkage. All children aged <16 years at diagnosis with primary malignant tumours, diagnosed and registered between 1990 and 2004, and living in cantons covered by a cantonal registry were included in the analysis. For patients with imperfect matches, a chart review in the central archive of the SPOG and in participating clinics was performed to identify data entry errors.

Results: 22.1% (238/1077) of patients recorded in cantonal registries were not registered in the SCCR. Of these, 15.7% (169/1077) had never been in a PCC while 6.4% (69/1077) had been in a PCC but were not registered in the SCCR, due to incomplete data flow. All age groups and all diagnoses were involved, but children suffering from malignant bone tumours/soft tissue sarcomas and from malignant epithelial neoplasms, and older children were least likely to have been treated in a PCC. The proportion of patients treated in a PCC increased over time ($p<0.0001$) such that in 2000-2004, only 8,9% were not treated in a PCC.

Rationale and significance: A comparatively high proportion of childhood cancer patients in Switzerland was not treated in a PCC and may therefore have not received best available care. Based on these findings we are currently developing a standardised protocol for regular future cross-validation between these databases, and we have begun to recruit cases from other sources than PCCs (cantonal cancer registries, pathology reports, other hospitals).

Study team

Applicants: Egger M, Kuehni CE. Institute of Social and Preventive Medicine, University of Bern; Ess S. VSKR, St. Gallen; Von der Weid N. Paediatric Oncology, CHUV Lausanne. **Project team**: Adam M, Kuehni CE, Zwahlen M, Michel G. Institute of Social and Preventive Medicine, University of Bern; Von der Weid N. Paediatric Oncology, CHUV Lausanne

Publications

Original peer-reviewed papers

Adam M, von der Weid NX, Michel G, Zwahlen M, Lutz JM, Probst-Hensch NM, Niggli F and Kuehni CE for the Swiss Paediatric Oncology Group (SPOG) and for the Swiss Association of Cancer Registries (ASRT). Which childhood cancer patients fail to access specialized care? *submitted.*

Michel G, von der Weid NX, Zwahlen M, Adam M, Rebholz CE, Kuehni CE. The Swiss Childhood Cancer Registry: Rationale, organisation years 2001-2005. *Swiss Med Wkly 2007;137(Suppl.35-36):502-9.*

Published abstracts

Adam M, Von Der Weid NX, Michel G, Zwahlen M, Ess S, Kuehni CE. Which childhood cancer patients fail to access specialised paediatric oncology care? *Swiss Med Wkly 2008;138:39S.*

Project 7 - Validating date and cause of death information in the SCCR against death certificate information from the Swiss Federal Statistical Office

Aims: This study matched the Swiss Childhood Cancer Registry (SCCR) patients (N=4856) to information from official death certificates recorded by the Swiss Federal Statistical Office (SFSO), to validate SFSO death certificate information and to update information on vital status in the SCCR using an independent information source.

Methods: First, anonymous records from both databases were matched using probabilistic record linkage techniques. For cases with discordant or missing information, further analysis was performed to identify predictors and possible causes for the discrepancy, using detailed demographic, clinical and healthcare information provided in the SCCR database. Where necessary, an additional chart review using the SPOG central archive and hospital records was performed.

Results: These are summarized in the final report, which can be obtained from the authors.

Study team

Applicants: Kuehni CE, Zwahlen M, Egger M. Institute of Social and Preventive Medicine, University of Bern; Von der Weid N. Paediatric Oncology, CHUV Lausanne. **Project team**: Michel G, Sturdy M, Strippoli MPF. Institute of Social and Preventive Medicine, University of Bern

Publications (Final report)

Michel G, Sturdy M, Zwahlen M, Strippoli MPF, von der Weid NX, Kuehni CE. Validating date and cause of death information in the Swiss Childhood Cancer Registry against death certificate information from the Swiss Federal Office of Statistics. *Bern: Dept. of Social and Preventive Medicine, University of Bern; Dec 2005.*

5 Review of activities 2007 – 2009

5.1 New Database

During 2006/2007, a new electronic database was developed for the SCCR by Malcolm Sturdy, and in June 2007 all data were successfully migrated and final modifications were made on the new database. Most data could be migrated automatically. However, certain pieces of information needed to be transcribed by hand. This relates for instance to information which had been stored as text in comment fields, while the new database stores them as variables in numeric format. Also, in several instances, information written in one single text field needed to be separated into several fields (for instance, addresses of referring physicians are now stored in separate fields for street, house number, town and postcode). The most important modifications were done immediately, but other information which is not immediately needed and involves a lot of work will be transcribed during the next years.

The database system

The SCCR database is an SQL database with an ACCESS user interface. It is hosted on a secure SQL server at the ISPM and allows different users on different computers to access the database via the ACCESS user interface. The data is stored encrypted on the server and depending on the user only certain parts of the database can be accessed. Predefined users are: System administrator, Data entry (non-anonymous); Data view (non-anonymous); Data view (anonymous).

The database structure

The database has a relational structure (**Figure 8**). For every patient one record is created with one or more linked records containing address information, information about the paediatrician, treating institution, prior disease, late effects, follow-up and external links and non-clinical studies (a detailed description of each variable contained in the SCCR database is available in a separate document). Every patient can also have one or more tumour records. For every tumour record one or more records with information about diagnosis address, pathology, cytology and relapse can be created. And for every tumour also one or more therapy record can be created which can again have one or more records about information on radiotherapy, surgery, chemotherapy and transplantations.

Detailed descriptions of the variables collected in the database and of the data collection form (basic data form) can be obtained from the SCCR (childhoodcancerregistry@ispm.ch or kinderkrebsregister@ispm.ch).

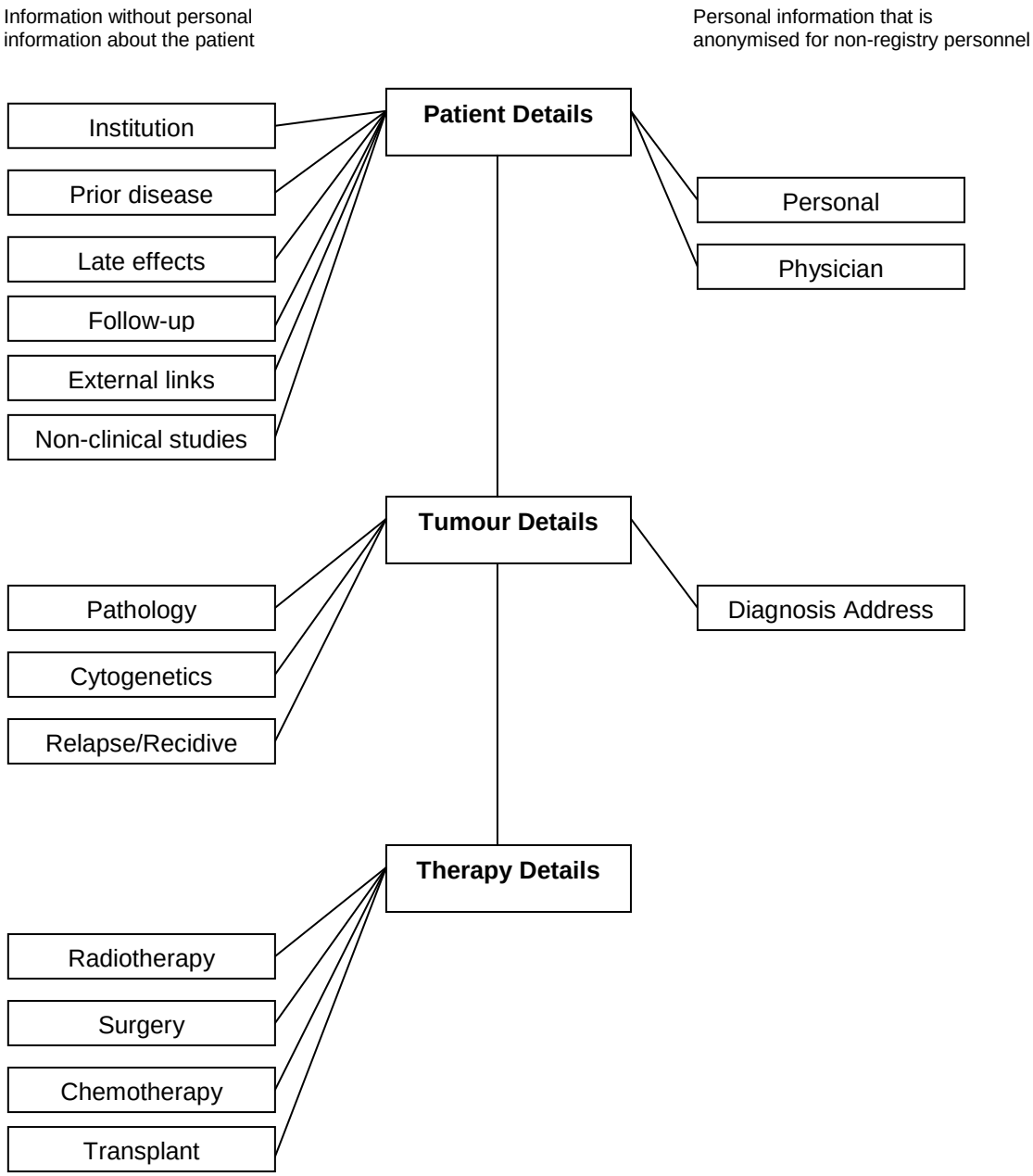
Data protection measures

The database is stored on a secure server in the ISPM, which is regularly being backed-up. It can only be accessed via a personal computer with a personal password. The person data themselves are only accessible with an additional password for predefined users. Each access to the database is registered and identified.

Additional documents

All additional information which the SCCR receives as paper documents (pathology or histology reports, other medical reports) are scanned and saved as picture in pdf format (so that the documents cannot be searched for names). All documents are then saved on the secure, password-protected server and can be linked, if necessary, to the SCCR record using the patient ID number. All paper documents are then destroyed.

Figure 8 – Relational structure of the SCCR database



5.2 New Homepage

In 2008, a new Homepage for the SCCR was created by Philipp Läuppi, which can be very easily updated. It is available in four languages (German, French, Italian and English) and can be accessed via:

www.kinderkrebsregister.ch

www.registretumeursenfants.ch

www.registrotumouripediatrici.ch

www.childhoodcancerregistry.ch

5.3 General exemption for cancer registries from the Swiss Federal Commission of Experts for Professional Secrecy in Medical Research

Since 1993, the act on professional secrecy for medical professions (Art. 321 StGB) forbids to communicate and collect non anonymous data for medical research. Exceptions (described in Art. 321bis StGB) are regulated by the Swiss Federal Commission of Experts for Professional Secrecy in Medical Research. Such exceptions can be afforded if the research cannot be done with anonymous data, if it is impossible or extremely difficult to obtain informed consent, if the research is of high public health relevance and if patients are informed of the project and are given the opportunity to refuse transfer of their data (right of veto). Three different permissions can be given: hospital permissions for single hospitals, special permissions ("Sonderbewilligung") for specific projects, and general registry permissions.

Between 2004 and 2007, the SCCR had a special exemption ("Sonderbewilligung"). This permission allowed collecting non-anonymous information on patients from several sites (SPOG clinics). For new patients and those still in medical follow-up, written informed consent was collected. Patients who were no longer in follow-up were informed of the existence of the registry using several approaches (newspaper adverts, information via parents and patients organisations).

While this system worked well for patients treated in Paediatric Cancer Centres from the SPOG, it did not allow data exchange with other institutions (other hospitals, cantonal cancer registries, pathology laboratories) because it is impossible to obtain informed consent in these situations.

A research project conducted in the years 2006-2007 described completeness of case registration in the SCCR by comparing the SCCR dataset with case records in the cantonal cancer registries (see chapter 2.2.4 and chapter 4.2, project No 6) and found, that during the period 1990-2004, 22% of cases registered in cantonal cancer registries were not recorded in the SCCR. Therefore, patients need to be registered from now on from additional sources as described above.

To enable this, the SCCR applied in April 2007 for a general registry approval by the Swiss Federal Commission of Experts for Professional Secrecy in Medical Research. This was obtained in June 2007 and permits the collection of data on cancer in children and adolescents throughout Switzerland without first obtaining written consent. At the time of diagnosis all patients and their parents are informed by their doctor about the registry and they can ask their treating doctor not to forward their data (veto power). Records of these patients are completely anonymised.

Huge efforts were made to inform all patients and their families, and all physicians in Switzerland about the registry, using various approaches (publications in official medical journals, oral presentations, letters to hospitals, physicians and parents organisations, and publication on the internet and in major newspapers). Information for patients is also available from hospital brochures, hospital notice boards, and parents and patients organisations. The patients' data are kept strictly confidential in accordance with the requirements of the Swiss Federal Commission of Experts for Professional Secrecy in Medical Research and data with personal information (names, addresses) are kept separately from the medical information.

6 Publications

Here, only selected publications are reported which have been published between Jan 2005 - Jun 2009, which are closely related to the SCCR or SPOG publications of clinical or epidemiological content where authors from at least two different SPOG centres contributed. Additional publications related to the SCCR and the SPOG can be found on the SCCR website: www.childhoodcancerregistry.ch and on the SPOG website: www.spog.ch.

6.1 Peer-reviewed publications

2009

1. Adam M, von der Weid NX, Michel G, Zwahlen M, Lutz JM, Probst-Hensch NM, Niggli F, Kuehni CE for the Swiss Paediatric Oncology Group (SPOG) and for the Swiss Association of Cancer Registries (ASRT). Which childhood cancer patients fail to access specialized care? *submitted.*
2. Michel G, Rebholz CE, von der Weid NX, Bergstraesser E, Kuehni CE. Psychological distress in adult survivors of childhood cancer: the Swiss Childhood Cancer Survivor Study. *submitted*.
3. Adam M, Rebholz CE, Egger M, Zwahlen M, Kuehni CE. Childhood leukaemia and socioeconomic status: what is the evidence? *Radiat Prot Dosim 2009;132:246-54.*
4. Wehrli LA, Braun J, Buetti LN, Hagleitner N, Hengartner H, Kühne T, Lüer S, Ozsahin H, Popovic MB, Niggli FK, Betts DR, Bourquin JP. Non-classical karyotypic features in relapsed childhood B-cell precursor acute lymphoblastic leukaemia. *Cancer Genet Cytogenet 2009;189:29-36.*
5. Zehnder A, Fisch U, Hirt U, Niggl FK, Simon A, Ozsahin H, Schlapbach LJ, Ammann RA. Prognosis in pediatric hematologic malignancies is associated with serum concentration of mannose-binding lectin-associated serine protease-2 (MASP-2). *Pediatr Blood Cancer 2009;53:53-7.*

2008

6. Asner S, Ammann RA, Ozsahin H, Beck-Popovic M, von der Weid NX. Overweight and obesity in long-term survivors of childhood acute lymphoblastic leukemia. *Pediatr Blood Cancer 2008;51:118-22.*
7. Michel G, von der Weid NX, Zwahlen M, Redmond S, Strippoli MPF, Kuehni CE. Incidence of childhood cancer in Switzerland: the Swiss Childhood Cancer Registry. *Pediatr Blood Cancer 2008;50:46-51.*

2007

8. Michel G, von der Weid NX, Zwahlen M, Adam M, Rebholz CE, Kuehni CE. The Swiss Childhood Cancer Registry: rationale, organisation and results for the years 2001-2005. *Swiss Med Wkly 2007;137:502-9.*
9. Röösli M, Michel G, Kuehni CE, Spoerri A. Cellular telephone use and time trends in brain tumour mortality in Switzerland from 1969 to 2002*. Eur J Cancer Prev 2007;16:77-82.*

2006

10. Kuehni CE, Zwahlen M. Commentary: Numerous, heterogeneous and often poor – the studies on childhood leukaemia and socioeconomic status*. Int J Epidemiol 2006;35:384-5.*
11. Brown AE, Leibundgut K, Niggli FK, Betts DR. Cytogenetics of pineoblastoma: four new cases and a literature review. *Cancer Genet Cytogenet 2006;170:175-9.*
12. Landolt MA, Vollrath M, Niggli FK, Gnehm HE, Sennhauser FH. Health-related quality of life in children with newly diagnosed cancer: a one year follow-up study. *Health Qual Life Outcomes 2006;4:63.*
13. Reid AG, Seppa L, von der Weid N, Niggli FK, Betts DR. A t(12;17) (p13; q12) identifies a distinct TEL rearrangement-negative subtype of precursor-B acute lymphoblastic leukemia. *Cancer Genet Cytogenet 2006;165:64-9.*
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7 Abbreviations

AML	Acute Myeloid Leukaemia
BMT	Bone Marrow Transplantation
CANUPIS	Childhood Cancer and Nuclear Power Plants in Switzerland
CHUV	Centre Hospitalier Universitaire Vaudois
CNS	Central Nervous System
DNA	Deoxyribonucleic acid
ENCR	European Network of Cancer Registries
GCCR	German Childhood Cancer Registry, Mainz, Germany
HUG	Hôpitaux Universitaires de Genève
HRQoL	Health Related Quality of Life
IACR	International Association of Cancer Registries
IARC	International Association of Research in Cancer
ICCC-3	International Classification of Childhood Cancer, Third revision
ICD-10	International Classification of Diseases and Related Health Problems, Tenth revision
ICD-O-3	International Classification of Diseases for Oncology, Third edition
ISPM	Institute of Social and Preventive Medicine, Bern
LCH	Langerhans cell histiocytosis
NICER	National Institute for Cancer Epidemiology and Registration, Zurich
NPP	Nuclear Power Plants
NRCT	National Registry of Childhood Tumours, Oxford, England
PANCARE	Pan-European Network for Care of Survivors after Childhood and Adolescent Cancers
PCC	Paediatric Cancer Centre
PNET	Primitive Neuroectodermal Tumour
POG	Pediatric Oncology Group
SCCR	Swiss Childhood Cancer Registry
SCCSS	Swiss Childhood Cancer Survivor Study
SES	Socio-economic status
SFSO	Swiss Federal Statistical Office
SNC	Swiss National Cohort
SPOG	Swiss Paediatric Oncology Group
SSKK	Schweizerische Stiftung für klinische Krebsforschung
STS	Soft Tissue Sarcoma
VSKR /ASRT	Association of Swiss Cancer Registries
WHO	World Health Organisation

8 Appendix: Classification of childhood cancer in the SCCR

ICCC-3

The third edition of the International Classification of Childhood Cancer (ICCC-3) represents the standard for presentation of international data on childhood cancer incidence and survival[8]. It applies the rules, nomenclature and codes (morphology, topography and behaviour) of the ICD-O-3. Furthermore, ICCC-3 categories are defined in conformity with international classifications of the pathology and genetics of childhood cancers. In the ICCC-3, three hierarchical levels have been developed: level one consists of 12 main diagnostic groups and level two of 47 diagnostic subgroups. These two levels of the ICCC-3 allow standardised comparison of the broad categories of childhood tumours. Level three, an optional "extended" classification, comprises two to eleven divisions of selected diagnostic subgroups. The division of some diagnostic subgroups, e.g. leukaemias and Non-Hodgkin lymphomas, reflects the availability of detailed cytogenetic or molecular information that permits homogeneous groups of tumours to be distinguished within them and thus allows their separate study. Most childhood cancer registries only use level one and two. Only malignant neoplasms are classified in ICCC-3, with the exception of non-malignant intracranial and intraspinal tumours. Tumours known to occur only rarely in young patients are also included in ICCC-3. The ICCC-3 is used if data are compared with other childhood cancer registries.

ICD-O-3

The third edition of the International Classification of Diseases for Oncology (ICD-O-3)[9] has been developed by a working group hosted by IARC/WHO. The morphology code for neoplasm has been revised, especially for lymphomas and leukaemias. In contrast to the ICD-10 classification, ICD-O-3 uses only one set of four characters for topography (based on the malignant neoplasm section of ICD-10). The topography code remains the same for all neoplasms of that site. The behaviour code is incorporated as the fifth digit in the morphology field. It identifies whether the tumour is malignant, benign, of uncertain or unknown behaviour, in situ, presumed to be primary or secondary. ICD-O-3 is used to compare data with general cancer registries.

ICD-10

The International Statistical Classification of Diseases and Related Health Problems (ICD)[10] permits the systematic recording, analysis, interpretation and comparison of mortality and morbidity data collected in different regions and at different time periods. The ICD has become the international standard diagnostic classification for all general epidemiological purposes. The ICD-10 classification comprises three volumes: Volume 1 contains the main classifications; Volume 2 provides guidance for users of the ICD; and Volume 3 is the alphabetical index to the classification. Classification is divided into 21 chapters. The first character of the ICD code is a letter. Each letter is associated with a particular chapter, e.g. the letter D is used in both chapters II "Neoplasms" and chapter III "Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism". The topography code in Volume 3 describes the site and the behaviour of the neoplasm: malignant, secondary or metastatic, in situ benign or unknown behaviour. The morphology codes listed in Volume 1 are the same as those used in the special adaptation of the ICD for oncology, the ICD-O (-2).

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